

STRATEGIES for MINDFUL LIVING

Courtesy of UAB Employee Assistance & Counseling Center

Advice for Caregivers

The COVID-19 pandemic has presented an additional set of challenges for already overworked caregivers. National Alliance for Caregiving President and CEO C. Grace Whiting, J.D., addresses these challenges and offers advice for caregivers during this difficult time:

Q: What are some challenges caregivers are facing during the COVID-19 pandemic?

A: In general, caregivers face challenges to their mental health, their physical health, and their financial health. In the National Alliance for Caregiving's "Caregiving in the U.S." 2020 study, one out of five caregivers said they felt isolated. Nearly 40 percent of caregivers say they wanted to have access to respite care, but only 14 percent of caregivers actually used respite care. A number of caregivers said their health actually got worse because of caregiving, and likewise, 50 percent of those who were working said they had no access to paid family leave. Nearly half said they experienced financial strains — anything from



Whiting

paying bills late, not paying mortgage, giving up savings, to taking out debt. COVID-19 has made things really hard for families. What COVID does is it adds complications. It creates new uncertainty for caregivers.

COVID-19 has also made things more challenging for working caregivers.

Working caregivers already experience some sort of negative impact on their career because of the challenges of working and giving care.

Q: How are caregivers dealing with their mental health during COVID-19?

A: There are two separate caregiving scenarios.



There's the caregiver at home with the person they are caring for that doesn't have access to respite care right now. That's challenging because they don't get a break. When we look at the data, people who live with the person they are caring for feel more isolated. It's not just the physical proximity to other people that matters. What matters is the ability to have a real connection with other humans. That can be hard to recreate with Zoom or telephone calls. I think people are starting to think through what that kind of support looks like. I wouldn't underestimate the importance of going for a walk around the block or participating in an appropriately socially distanced activity, because people need human interaction.

On the other hand, there are long-distance caregivers — the people who are not in the same place as the person they are caring for. Communication plays an important role for these caregivers. Make sure you're communicating frequently with the person that you take care of and that you're understanding what their needs



are, and how they are managing their care plan. That's where I think tech can be helpful. At the same time, be mindful that the person you're caring for is an independent person with their own human dignity. You want Mom to be safe, but you also want Mom to live her life. It's important to be mindful of the boundaries. Even though you may worry because of COVID-19, your mom may not. Be mindful of people's independent right to live the way they want to live.

Q: How has COVID-19 made it difficult for people living in assisted living and their caregivers?

A: It varies a lot from place to place and the type of facility. The biggest challenge many families are feeling is that it's not clear when and if they are going to be allowed to stop sending a care partner into the facility. This is particularly problematic for someone with dementia. Because of COVID-19, caregivers are often not allowed to accompany the person they are caring for at various facilities. The challenge with that is that if you have someone who can't necessarily

advocate for themselves, who is going to look out for that person, or explain why they are in the facility, or why everyone is wearing masks, or what COVID-19 is? Those are the kinds of challenges that people are trying to figure out.

Q: What are some tips you have for caregivers during this difficult time?

A: One of the questions I really think is worth spending some time on, is how do you find meaning and purpose in the middle of this trauma that we are all collectively experiencing? Caregivers already know how to do some of that. We know from the data that 51 percent said they have a sense of meaning and purpose from caregiving. There is this aspirational feeling of, "I say that I love this person, and that means I love them when we have those happy moments, when we're celebrating and we've got cake, but it also means I'm willing to put that love into action and help them go to the bathroom or give them an injection or change a colostomy bag or manage their checkbook." Caregiving is also all of those nitty gritty activities that we don't always think about because they aren't as warm and fluffy. Many caregivers sometimes forget that it's not just the one person they are caring for, or the couple people they are caring for. We're talking about 53 million Americans who are basically the backbone of our healthcare system and our long-term care system. They're filling all those spaces where healthcare silos don't connect. I think one thing that could help caregivers is to try to reframe what's happening — this is us versus the disease, me versus this disability, it's not me versus the person I'm caring for.